

Systems Change for Community Living

Semi-Annual Report

Time Period: October 1, 2002 to March 31, 2003.

Please describe only those activities that occurred in this six-month period.

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Grant Information:

Grant Number 18-P-91568/7-01
Grant State Nebraska
Name of Grantee Nebraska Department of Health & Human Services
Title of Grant Real Choice for Nebraskans
Type of Grant Systems Change Grant for Community Living
Amount of Grant \$2,000,000
FY 2001

Contact Information: (Complete this section only if information has changed from that listed in the *Compendium of Systems Change Grants, Second Edition*, February 2003.)

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MAJOR MILESTONES / ASSESSMENT OF CURRENT STATUS

A. Goals, Objectives, and Activities:

Goal #1: **Implement a consumer-directed model of services coordination and services delivery.**

- Develop and convene a Consumer Task Force to provide overall guidance and gain consensus on choice definition, risk, and guiding principles for systems development. **(F – Activity is complete)**
 - **Membership on Consumer Task Force:** Membership on the Consumer Task Force has varied as some members were no longer able to serve on the committee due to job changes, relocation, etc. New members have been added to replace outgoing members in an attempt to keep a balanced representation of disability groups. Currently efforts are being made to expand and recruit CTF membership to achieve better representation of cross-cultural populations and mentor matching.
 - **Consumer Task Force Meetings:** In the past six months, three CTF meetings were conducted on November 18, 2002, January 13, 2003, and March 10, 2003.
 - **CTF members elected Chairperson and Vice Chairperson:** At the November 18, 2002 Consumer Task Force meeting, a chairperson and vice-chairperson were chosen by vote to preside over meetings. Duties of the chair include meeting facilitation (previously performed by a professional facilitator) and providing consumer input on the development of meeting agendas.
- Develop a system-wide philosophy and organizational culture that supports consumer-directed services and supports across the life span. **(A – Activity has been initiated and is being completed on schedule)**
 - **Published Proceedings from Real Choice Town Hall Meetings:** Approximately three thousand brochures reporting the results of the 2002 Town Hall Meetings were developed and disseminated throughout Nebraska. The report summarized the findings from the eight Town Hall Meetings conducted in September and October 2002.
 - **Real Choice Logo:** The Consumer Task Force chose a logo to represent the Real Choice philosophy and principles.
 - **Training Subcommittee:** Since October 2002, the Training subcommittee has provided input on the “Consumer Training Work Plan – 2003” and the Services Coordination Core Competencies.



- **Cultural Awareness Subcommittee:** The Cultural Awareness Subcommittee provided direction on the January 2003 Bilingual Hispanic Town Hall meeting; developed a definition of Cultural Competence (approved by the CTF on March 10, 2003); and met with the Office of Minority Health and Human services on the development of a cultural awareness curriculum to become part of the Real Choice training.
- **Bilingual Town Hall Meeting:** On January 19, 2003 the Real Choice for Nebraskans project co-sponsored a bilingual Town Hall Meeting in Omaha, NE. Fifteen people were in attendance. Participants rated the meeting as very informative and were interested in being involved with future events.
- **Public Television Programs Addressing Cultural Diversity and Real Choice:** Two telecasts were conducted to present information about the Real Choice Project to culturally diverse groups. The presentations were given over public television on a channel devoted to diverse cultures. Information was presented in an interview format and viewers were encouraged to call the television with questions while the program was on the air. One presentation focused on individuals from the African- American community and the other addressed individuals from the Hispanic community.
- **Statewide Teleconference on Self-Directed Supports:** The Real Choice Project provided financial assistance for people to participate in an interactive video teleconference entitled “Self-Directed Supports: Tools for Implementation.” The teleconference was offered to 13 sites across Nebraska on March 5, 2003. Tara Asai of the Oregon Technical Assistance Corporation presented on incorporating concepts of self-determination into current practice as we move to a more self-directed service system. A total of 155 participants attended, including 84 Services Coordinators and 5 Consumers sponsored by the project.
- **Real Choice Presentations at Statewide Conferences:** Presentations to provide information on the grant goals and activities, obtain input/feedback on barriers to self-directed services, and explore ways participants could implement consumer directed supports were given at the following conferences:
 - *Association for Community Professionals and American Association on Mental Retardation/Nebraska Conference:* One hundred twenty-five community-based direct support workers and administrators who provide supports to individuals with developmental disabilities attended the conference.
 - *People First Conference:* Approximately 450 consumers attended the conference.
 - *Native American Families of Children with Special Needs Conference:* Approximately 49 family members of Native American heritage attended the presentation.

- Analyze current services coordination across systems, and evaluate federal and state policies/regulations/practices to determine where barriers to, and opportunities for, flexibility exist. **(F – Activity is complete)**
 - **Services Coordination Core Competencies:** A document describing Services Coordination Core Competencies was developed and approved by the Services Coordination Subcommittee. Approval by the Consumer Task Force is pending. Efforts are being made to ensure that all of the competencies are addressed in the Real Choice training curriculum that is to be implemented statewide.
- Design and develop a sustainable, integrated, flexible, customized system that enables consumers throughout their life spans to make decisions throughout the service planning process to the extent, and in the areas, that they choose. **(A – Activity has been initiated and is being completed on schedule)**
 - **Pilots:** Two pilots are in the process of being implemented:
 - The Consumer Task Force adopted the Harvest Project, a cross-agency program that provides services based on consumer need and preference, as a Real Choice pilot in January.
 - A technical tool to review rules & regulations for barriers has been developed, and work began in March to identify specific areas to pilot the tool. (See goal #3)

Goal #2: Improve consumer access to, and information about, supports and services.

- Improve access to the state service system so that eligible consumers receive the best information regardless of the program through which services may have been initially obtained. **(A – Activity has been initiated and is being completed on time.)**
 - **Statewide Philosophy:** To enhance long term sustaining system change, the Real Choice Project allocated funds for use by HHS Service Area Administrators to incorporate training on self-directed philosophy for all staff in the HHS system.
- Coordinate existing information and referral systems through standardization of guidelines and marketing materials. **(F – Activity has been completed within funding limits. See Goal #5)**

Goal #3: Develop a system that allows consumers from various disability systems to access and receive needed services through a more transdisciplinary approach to service delivery across systems.
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- Analyze the current system to identify barriers to and opportunities for enhancing cross-system access and coordination of services, and start the legislative amendment process in order to bring about system redesign. **(A – Activity has been initiated and is being completed on time.)**
 - The Rules & Regulations Review Subcommittee developed a tool, based on our consumer-directed guiding principles, to review existing rules and regulations for barriers to consumer choice. The subcommittee, with input from the Consumer Task Force, has refined the tool and identified the top barriers to regulatory process by population in order to pilot the tool in a regulatory review process.

- Standardize and simplify the enrollment of agencies and individuals to become providers in order to give consumers greater flexibility and more options in selecting providers. **(E – Activity not scheduled in this report period)**
- Identify and increase the availability of approved community services and support providers. **(B – Activity has been initiated, but my not be completed on schedule)**
 - Real Choice for Nebraskans is coordinating efforts with existing subcommittees established to examine Personal Assistance Services and Transportation in Nebraska. A consumer liaison from these committees attends and reports to the Consumer Task Force on a regular basis. Additionally, the Consumer Task Force is in the process of electing a consumer member to serve on each of the committees. The committees are currently examining what is available in the state in order to identify strategies to achieve this activity.

<p>Goal #4: Implement a quality management system that ensures the health and well-being of consumers through consumer-directed monitoring and improvement.</p>
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- Based on consumer input and work by the Consumer Task Force, NHHSS, and the Munroe Meyer Institute (MMI), develop desired consumer outcome measures to ensure needs are met through high quality long-term support systems that enable consumers to make real choices about how they live and participate in their communities. **(F – Activity is complete)**
- Design and implement a sustainable statewide quality management system that effectively monitors and makes improvements by using consumer-focused quality assurance measures. **(A – Activity has been initiated and is being completed on time.)**
 - **Quality Assurance Subcommittee:** A Quality Assurance Subcommittee was established to provide guidance on the development and implementation of a consumer-directed quality assurance system. The subcommittee consists of 20 members representing HHS administration, quality assurance professionals, and consumers. Review of current quality assurance processes is being conducted.
 - **Presentation on Risk and Quality Management:** At the March 10, 2003 Consumer Task Force meeting, a presentation was made addressing the topics of risk and quality management efforts in other states.
 - The Consumer Task Force has invited a representative of the Kansas Department of Social and Rehabilitation Services to present on quality assurance measures used in their program. The Kansas program is successfully implementing consumer-directed services across disability groups.

Goal #5: Make available to consumers and agencies a comprehensive, statewide resource database of health and human services.

- Set uniform standards, practices, and methods pertaining to collection, management, use, and promotion of data for resource directories across state agencies and organizations. **(F – Activity has been completed within funding limits)**
 - The statewide Data Team finalized 22 recommendations on standards, protocols, inclusion/exclusion criteria and data sharing for a coordinated resource data structure in Nebraska.
 - A subcommittee was established to research methods currently being used to gather information on resources. The subcommittee surveyed consumers, advocacy groups, services coordinators and others to determine preferred method to access resources. The survey also provided information on the use and effectiveness on the Nebraska Resource and Referral System (the current Internet based resource database being used by the state). Based on survey findings, the committee developed seven recommendations for development of, or improvement to, an information and referral system that provides access to services and supports.
- B. Please describe the types of activities that consumer partners, private partners, and public partners have been involved in since September 30, 2002 (e.g. participated in advisory or oversight meetings, reviewed grant related materials, engaged in planned grant activities, etc.).

Please describe activities separately for each type of partner. If partners participated in some of the same activities (e.g., attending committee meetings), you do not have to describe them separately. Just clarify which partners participated in joint activities, and their respective roles. ***Please limit your response to this question to one page.***

1. Consumer partners:
 - Consumers are members of all work groups involved in this grant: Training Subcommittee, Subcommittee on Cultural Competency, Services Coordination Subcommittee, Quality Assurance Subcommittee, and Rules & Regulations Review Subcommittee.
 - A consumer chair was elected to facilitate all Consumer Task Force meetings. The chair and five additional consumer members comprise the Consumer Task Force Executive Committee. The Executive Committee serves in an advisory capacity to the HHS Real Choice Steering Committee and provides input on agenda planning and other pending activities of the Consumer Task Force.
 - Consumers serving on the Consumer Task Force have presented on the Real Choice Project at statewide events.
 - Two consumer members of the Executive Committee were chosen by the Consumer Task Force and funded by the grant to attend the CMS “Living and Working in the Community, 2003” Conference in Baltimore, MD.

- A consumer liaison representing Nebraska’s Medicaid Infrastructure Grant was invited to attend Consumer Task Force meetings and activities to gather and share information on the two grants’ commonalities. In turn, a consumer member of the Consumer Task Force was selected to serve in the same capacity to the Medicaid Infrastructure Grant’s Project Advisory Committee’s activities.

2. Private partners:

- Providers serve on the Consumer Task Force and various subcommittees under the Real Choice grant.
- Parent Training Information of Nebraska and the League of Human Dignity are addressing training issues as subcontractors to Real Choice.
- Private agencies, including representatives from the Harvest Project and the Indian Chicano Health Center’s Lay Advisor Project, have presented at Consumer Task Force meetings on their consumer-directed services.
- Statewide advocacy groups provided input to subcommittee work through surveys and assisted in distributing results of the 2002 Town Hall meetings to their membership.

3. Public partners:

- The Real Choice Health & Human Services Steering Committee is comprised of program staff across the grant’s targeted populations and serve as a direction-setting body and technical assistants to the Consumer Task Force and various subcommittees. Programs represented include Medicaid; Home & Community Based Waivers; Developmental Disabilities Council; Mental Health, Area Agencies on Aging; Children with Special Health Care Needs, Department of Education; Early Intervention; and the Social Services Block Grant.
- The University of Nebraska’s Public Policy Center and the University of Nebraska Medical Center’s Munroe-Meyer Institute are major contractors under the Real Choice grant.

C. Please describe how grant activities are being coordinated or integrated, if applicable, with other disability or long-term care programs, coalitions, grants (including Medicaid Infrastructure Grants and other CMS grants), or other groups working on the same or similar issues. *Please limit your response to this question to one page.*

- **Home & Community Based Waivers** – The Real Choice philosophy is being institutionalized in the Home & Community Based Waiver regulations, policies, and processes.
- **The Harvest Project** – This program, designed to “bring coordination and long-term continuity to the delivery of aging, mental health, and substance abuse services to vulnerable older adults,” was selected to receive Real Choice grant funds as a pilot of client-directed services and cross-agency methodology.

- **Medicaid Infrastructure Grant** - Consumer liaisons have been elected to gather and disseminate information between the Real Choice for Nebraskans project and Nebraska's Medicaid Infrastructure Grant. Additionally, work is being coordinated between the two systems change grants through subcommittee efforts addressing personal assistance services and transportation in Nebraska.
- **Nursing Home Transition Grant** – The client-directed approach piloted in the Nursing Home Transition Grant has resulted in a new service in the Aged & Disabled Waiver called “Take Me Home.” This service gives the client a set amount of funds to use on needed services, furnishings, deposits, etc. to move to independent living. The name “Take Me Home” was chosen to move away from the usual jargon that results in names of services that are not understandable to the public.
- **Medicaid Hospice Services** – Draft regulations for a new Medicaid Hospice service propose a client-directed approach to end of life care. Members of the Real Choice Consumer Task Force provided input into the regulatory process

D. Please indicate if your project has produced any outreach, educational, or technical materials or reports that you believe would be useful to Grantees and others working on the same issues. *Please limit your response to this question to half a page.*

- **“Report on Town Hall Proceedings: What did we learn?”** – A color brochure summarizing the input received at the 2002 town hall meetings was produced and disseminated across the state to consumers, advocacy organizations, providers and others. The Munroe-Meyer Institute, a contractor to this grant, prepared an in-depth technical report as supporting material to the brochure.
- **“Definition of Cultural Competence”** – This definition, prepared by the Cultural Competency subcommittee, was approved by the Consumer Task Force in March 2003. It will be used in the development of all training materials.
- **Real Choice for Nebraskans Web site** – Online information regarding Real Choice, including events, meeting minutes, subcommittee materials, federal reports and other information is available for any person wanting additional information on Nebraska's Real Choice project. The site can be accessed at www.hhs.state.ne/ags/realchoice/.

E. Please describe the major challenges you have faced in implementing grant activities. *Please limit your response to this question to half a page.*

As with any systems change activities, it is difficult for those who currently implement programs to have the time to work on change while maintaining their programs. Current budget problems also overshadow the goals of the grant. Another major challenge is helping people understand how systems change is a lengthy process. Incorporating cultural competence into all phases of the grant continues to be an ongoing challenge. A special task force has been developed to address this issue

F. Have you had to revise any of your goals or activities since September 30, 2002? If so, please describe why you had to make revisions, and describe the changes you have made. *Please limit your response to this question to half a page.*

No revisions have been made.

- G. Is there specific assistance that the CMS Central Office or your CMS Regional Office could provide to help you achieve the goals specified in your grant? ***Please limit your response to this question to half a page.***

None at this time.

- H. Please describe specific approaches, methods, or activities that you believe have been particularly effective or useful, and which you would recommend to others working on the same or similar issues. Include any information about critical steps or partners, pitfalls to avoid, and any particular activities that facilitated success. ***Please limit your response to this question to one page.***

Legislative change to Nebraska's Nurse Practice Act has allowed the client-directed approach to be incorporated in regulations for Personal Assistance Services. The change goes beyond the traditional nurse delegation. Clients are able to direct paraprofessionals in the performance of medical procedures. This legislative action is referred to as the "Tim Kolb Amendment" because Tim Kolb, a Nebraska resident, provided the major influence for this change. Tim currently serves as Consumer Liaison to the Real Choice Consumer Task Force.

- I. ***For Nursing Home Transition Grantees:*** Please provide any information you have about individuals who have been transitioned or diverted from a nursing facility using grant funds (e.g. age, gender, ethnicity/race, level of care need, primary diagnosis, activities of daily living needs, numbers of months in the nursing facility prior to transition and/or months in the hospital or other institution prior to diversion.) ***Please limit your response to this question to one page.***

- J. Is there anything else you would like to tell us about your project's activities since September 30, 2002? ***Please limit your response to this question to half a page.***

II. TECHNICAL ASSISTANCE

Please limit your response to the questions in this section to one page.

- A. During the last six months, what technical assistance did your project receive from the Community Living Exchange Collaborative: A National Technical Assistance Program (formerly known as The National Technical Assistance Exchange for Community Living)?

A number of teleconferences were arranged by the Exchange. Additionally, various "best practices" and research was shared with the state.

- B. What changes, if any, would you suggest in the way that technical assistance is being provided to make it more effective or timely?

We would continue to ask for state input and respond accordingly. We also would suggest that task forces such as “Community Based Waivers” include CMS officials as members/consultants.

- C. Did you receive any technical assistance from other sources (e.g., public or private partners or Grant consultants)? If so, please describe.

The University of Nebraska Medical Center Munroe-Meyer Institute is contracted under the grant to provide consultation in training services coordinators and on quality management across multiple programs and populations.

- D. Please describe the technical assistance that would be helpful as you complete the second year of your Grant’s activities.

Sharing the works of other states would be the most helpful form of assistance.

III. ENDURING SYSTEMS CHANGE

Please limit your response to the following question to one page.

- A. Have Grant activities resulted in any enduring changes to processes, programs, or policies that affect access to, and the availability, quality, and value of services provided to persons of all ages with disabilities or chronic illnesses?

By enduring change, we mean changes that will endure ***beyond the three year Grant*** period, for example:

Goal three of the Real Choice initiative is, “to develop a system which allows consumers from various disability systems to access and received needed services.” In the first year of the initiative, consumer input identified barriers that interfered with the achievement of the Real Choice goals. There was considerable input suggesting that some existing rules, regulations, and policies are not compatible with Real Choice principles and goals. As part of the grant efforts, a Rules & Regulations Committee was appointed to examine, assess, and determine the nature of the interface between Real Choice principles and HHS rules, regulations, and policy and to make recommendations for change as appropriate. This effort will result in enduring change because it accomplishes infrastructure change consistent with the goal of the Real Choice initiative.